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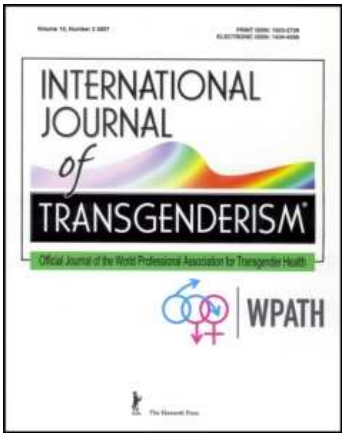

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The Future of GID NOS in the *DSM 5*: Report of the GID NOS Working Group of a Consensus Process Conducted by the World Professional Association for Transgender Health

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ABSTRACT. The *DSM-IV-TR* diagnosis Gender Identity Disorder Not Otherwise Specified (GID NOS) is used to describe individuals who have gender issues but do not meet the current criteria for GID. As part of a consensus process conducted by the World Professional Association for Transgender Health, the authors make the following recommendations for *DSM 5*: removal from the chapter on sexual disorders, more specific diagnostic criteria, retention of clinical significance criteria, and removal of exclusionary criteria of Intersex/Disorders of Sex Development. Changes to the existing clinical examples were also recommended, suggesting additional clinical examples that encompass a broader range of gender-variance and more commonly found transgender presentations. The diagnosis must reflect the severity of the clinical issues that represent legitimate identity experiences and possible need for gender-confirming treatments.

KEYWORDS. Transgender, transsexual, gender identity disorder (GID), gender identity disorder not otherwise specified (GID NOS), gender dysphoria, cross-dressing, castration, intersex, disorders of sex development, *DSM*, *DSM 5*, gender variance, genderqueer

The World Professional Association for Transgender Health (WPATH) assembled a number of work groups to participate in a consensus process designed to generate recommendations for the development of *DSM 5* (Knudson, DeCuypere, & Bockting, 2010/this issue). This is a report of the work group asked to consider the usefulness and validity of the diagnosis Gender Identity Disorder Not Otherwise Specified (GID NOS). In developing our ideas we relied upon a review of the scholarly literature, input from colleagues, and our combined extensive professional experience in treating diverse transgender populations.

GID NOS is the diagnosis given to individuals who present for treatment with gender-related

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issues but who do not fulfill the full criteria for gender identity disorder. This is a diverse group that includes people who have nontraditional gender identities and individuals who seek hormones or surgery to express their unique gender identities and who may not wish to live full time in the "other" gender role.

People with nontraditional identities have been represented in the literature on transgender themes for decades. Some literature comes out of personal experience, such as Kate Bornstein's *Gender Outlaw: On Men, Women, and the Rest of Us* (1994), some takes a historical perspective (Stryker, 2006), some, a sociological perspective (Ekins & King, 2001) or a queer-theory perspective, (Halberstam, 2005; Jagose, 1996). There is also a growing body of work relating to clinical practice (Benjamin, 1966; Bockting, 2008; Bockting & Goldberg, 2006; Burdge, 2007; Factor & Rothblum, 2008; Hage & Karim, 2000; Lev, 2004).

One subgroup of people who may not identify exclusively as male or female are now using the term *genderqueer* to describe their experience and/or identity. This group is particularly visible and vocal on college campuses in the United States. Jacobson and Donatone (2009), writing of the unique needs of "queer youth," say, "The queer youth of today are significantly different from the lesbian, gay, and bisexual youth of yesteryear. Group treatment must evolve to accommodate the ever-evolving needs of this cohort, in terms of both content and format. [Their] article conceptualizes queer youth in a more current way, integrating sexuality and gender identity with greater fluidity."

Though GID NOS is not mentioned by name in most of the professional literature above, the growing academic and clinical discourse focused on the inadequacy of traditional categories of gender to describe the full range of human experience has direct relevance to this diagnostic classification. This conversation among researchers and clinicians has been gaining momentum over the last decade. As Carroll (1999) wrote, "[T]he mental health field is accustomed to thinking of only two solutions [for gender dysphoria]: either changing the identity to match the body (i.e., accepting completely one's given physical gender and gender role) or changing the body to match the identity and adopting completely the identity of the other gender. Increasingly, clinicians and transgender individuals themselves are finding that these categories are inadequate to describe the possible resolutions to cross-gender experience" (p. 129).

In her book *Transgender Emergence* (2004), Lev reviewed the existing literature pertaining to gender variance and the direct implications for diagnostic issues and clinical practice. Below is an excerpt of her discussion of the many theoreticians, scholars, and clinicians who have addressed the need for new conceptions of gender.

> Behavioral scientists and clinicians are also beginning to develop alternative models that allow room for genderblending, bi-genderism, and flexible gender migration patterns. McKain (1996) wrote about mixed-sex people, Cole et al. (2000) presented a transgender model that allows for multiple sexes; and Bockting and Coleman (1992) offered a "comprehensive treatment model that recognizes a wide spectrum of gender identity disorders" (p. 131). More expansive models will allow gender specialists to move out of a gatekeeping model of assessment to a psychotherapeutic relationship that allows for clients' unique narratives within a clinical perspective that is humanistic and empowerment focused. (Lev, 2004, p. 145)

In spite of the growing literature on transgenderism, our research revealed that the diagnosis GID NOS is rarely discussed at any length or depth in books or scholarly articles. In most literature, GID NOS is simply defined within a larger discussion of the GID diagnosis. A paper by Hage and Karim (2000) was the one scholarly article we found devoted specifically to the diagnosis GID NOS. It contained a thorough discussion of the need for medical treatment and services for individuals who do not meet the full criteria for GID.

Hage and Karim (2000) noted that as far back as 1966, Harry Benjamin documented a continuum of different degrees of gender dysphoria. At one end of the continuum were people who achieved relief from gender dysphoria by

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cross-dressing and, at the other end, those who needed a complete gender transition including hormones, sex reassignment surgery, and a change of legal status (Benjamin, 1966). The latter group received a diagnosis of transsexualism. In between these two extremes were people who needed some, but not all, of the anatomical features of the other sex to decrease their feelings of gender dysphoria. These people could be considered as falling into the GID NOS group.

Hage and Karim (2000) demonstrated that throughout the research literature, there are indications of subsets of individuals of "transsexual" or "GID" samples who may, in fact, be more appropriately diagnosed with GID NOS. For example, data from Hage's Amsterdam cohort of patients for the period 1975 to 1995 showed that 24% of the male-to-female individuals who received hormonal treatment did not proceed to genital surgery. In the female-to-male group, 48% had only a mastectomy, and 13% did not have any surgery at all (Hage & Karim, 2000). We do not know from these data if these individuals wanted more surgery. However, the desire for some, but not all, of the physical characteristics of the other sex would qualify a person for a diagnosis of GID NOS. We suspect that some of the participants would have qualified for that diagnosis.

Outside of general discussions of the GID diagnosis, GID NOS is most often discussed in the context of cross-dressing, intersex issues or disorders of sex development, or penectomy and castration among people who do not meet the criteria for GID. These three groups are specifically mentioned among the clinical examples in the *DSM-IV-TR* (American Psychiatric Association, 2000).

Cross-dressers may wear the clothing of the other sex for many reasons and may request hormones or surgery to support their female presentations and/or to affirm the female aspect of their identity. Those whose cross-dressing is accompanied by significant levels of gender dysphoria, but who do not meet the criteria for GID, could reach a clinical threshold for a diagnosis of GID NOS. Intersex individuals have been excluded from a diagnosis of GID. The argument against including them in the GID diagnosis was summarized by Mazur, Colsman, and Sandberg (2007) as follows:

> Failure to differentiate between individuals with and without a clearly identifiable intersex condition may hamper studies of etiology and optimal clinical management. Given that our understanding of etiologic factors in GID in physically typical individuals (i.e. transsexuals) and in those with intersex conditions is incomplete, it would be prudent to consider them as separate entities when initiating an evaluation of GID. (p. 236)

According to the *DSM-IV-TR*, persons with an intersex condition who experience gender dysphoria are not eligible for a diagnosis of GID for children, adolescents, or adults but can be given the diagnosis of GID NOS. Under "associated physical examination findings and general medical conditions," the *DSM-IV-TR* specifies that "[i]ndividuals with Gender Identity Disorder have normal genitalia (in contrast to the ambiguous genitalia or hypogonadism found in physical intersex conditions)" (p. 579). Further, the definition of "302.6 Gender Identity Disorder Not Otherwise Specified" specifies that "[t]his category is for coding disorders in gender identity that are not classifiable as specific Gender Identity Disorder." Currently listed examples include "[i]ntersex conditions (e.g., partial androgen insensitivity syndrome or congenital adrenal hyperplasia) and accompanying gender dysphoria" (*DSM-IV-TR*, p. 582).

While it is clear that individuals with intersex conditions do have unique circumstances, these individuals may experience very similar gender issues typical of transsexual or transgender individuals. Heino Meyer-Bahlburg has written extensively about the similarities and differences between the experiences of transgender, transsexual, and intersex individuals. In his work he has explored the complex issues which would surround the of a GID diagnosis (Meyer-Bahlburg, 1994, 2005). Though there are arguments to be made for treating intersexual individuals outside of a GID diagnosis, the GID NOS Working Group believes that, when appropriate, intersex individuals should not be

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excluded. We recommend that such individuals be given a dual diagnosis when appropriate to indicate both intersex status and transgender identity. This would mean that they would not be excluded from the diagnosis of GID for children, adolescents, or adults or from receiving gender-related treatment.

Another group that has been included under the current *DSM-IV-TR* definition of GID NOS are individuals who have a "persistent preoccupation with castration or penectomy without a desire to acquire the sex characteristics of the other sex" (p. 582). Research has shown that there are individuals who identify as male-to-eunuch who fit this description and who are at high risk for self-injury or treatment by unqualified surgeons (Brett, Roberts, Johnson, & Wassersug, 2007; Johnson, Brett, Roberts, & Wassersug, 2007). These individuals experience their identity as eunuch as a form of gender identity. Johnson et. al. (2007) contend that although eunuchs are not very visible in contemporary society, they have been regarded as recognized members of various cultures throughout human history. In fact, they contend that eunuchs have been the most prevalent of all transgender identities across history and across civilizations. Eunuch-identified individuals who present for treatment today with clinical levels of distress or impairment may be denied medical services because they do not meet the full criteria for GID (Vale et al., 2010). As Wassersug, Johnson, and Vale stated:

> In order to ensure the safety and well-being of these individuals, a GID-NOS diagnosis that involves an extreme but singular desire for castration and/or a penectomy should not be considered any less serious than a GID with a focus on gender transition. The "NOS" designation should not mean that an individual with this diagnosis is denied surgical assistance when there is clear indication that the individual will seek surgery from non-professional providers or attempt self surgery. (R. Wassersug, T. Johnson, and K. Vale, personal communication, June 25, 2009)

GID NOS is intentionally constructed to encompass a wide range of individual experiences and presented in clinical practice. However, it may be described as an "orphan diagnosis." An orphan diagnosis is one that exists formally but is either rarely used or rarely studied. We believe that in this case, the GID NOS diagnosis is used but rarely studied. The diagnosis has found favor with clinicians who develop treatment plans for persons who seek hormonal and/or surgical interventions in the absence of significant gender identity concerns and/or in the absence of gender dysphoria that reaches clinical criteria for GID in children, adolescents, or adults. For example, some people who cross-dress and want to appear and feel more feminine but have no intentions of either cross-living or having sex reassignment surgery, nonetheless, may desire small doses of cross-sex hormones. Clearly, a diagnosis of GID would be inappropriate in these fairly common clinical situations, and GID NOS has fulfilled this need for a diagnostic category. Similarly, there are natal male individuals who, in the absence of gender dysphoria, request breast augmentation surgery or other feminizing surgery and who do not meet the full criteria for GID. These cosmetic procedures may require a diagnostic code, hence, the use of GID NOS in these situations by some clinicians.

RECOMMENDATIONS

The work group on GID NOS was given the charge to answer the following questions as part of the overall consensus-building process conducted by the World Professional Association for Transgender Health:

1. Should GID NOS remain in the *DSM 5*?
2. Should the diagnosis have a different name?
3. Where should a GID NOS diagnosis appear in the *DSM 5*?
4. Which diagnostic criteria do we propose for GID NOS?

We address each of these questions below.

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Should GID NOS Remain in the DSM 5*?*

The arguments in favor of keeping GID NOS in the *DSM* are similar to those for keeping the other gender identity diagnoses in the *DSM*. GID NOS is an appropriate diagnosis for those who meet the proposed criteria for GID NOS discussed below and, as such, may facilitate assessment and access to treatment for individuals who meet clinical significance criteria and are in need of clinical services. This is particularly important in countries with national health care systems, such as those commonly found in countries of the European Union, and is also important in other areas where private insurance companies cover services based on a formally recognized diagnosis. Individuals who meet the diagnostic criteria for GID NOS often seek care from mental health professionals. This is a reason for including GID NOS in the *DSM*, which attempts to describe conditions for which individuals might seek mental health care. The *DSM* also supports research by describing measurable parameters of the experience and by offering a definition of the condition to create consistency across studies. Thus, retaining the GID NOS diagnosis would also support research to improve the care and quality of life for transgender people. Furthermore, the diagnosis can have an impact beyond its clinical utility. For example, in some countries, a gender-related diagnosis is a necessary criterion for legal recognition in the preferred gender role. In those countries, individuals must submit evidence of a diagnosed condition in order to marry or obtain legal identity documents such as a driver's license, birth certificate, and other documents necessary for everyday life.

On the other hand, the work group considered a number of arguments against keeping GID NOS in the *DSM*. One argument is that any gender diagnosis has the potential to pathologize a natural variant of human experience. This concern is largely addressed by the fact that individuals who do not meet the criteria for distress and impairment do not receive the diagnosis. Another consideration is the evidence that the GID diagnosis may be misused to support persecution and that by removing it we remove one obstacle in the path of depathologization. Removal of the GID and GID NOS diagnoses could potentially support progress regarding a range of civil rights issues including anti-discrimination laws, child custody, adoption, and marriage (comparable to the removal of homosexuality).

Based upon the above considerations, there was some disagreement among work group members regarding whether the GID diagnosis should remain in the *DSM*. However, the work group did reach consensus that, if there will be a GID diagnosis in *DSM 5*, there will also be a need for GID NOS. Although the next version of the *DSM* may reflect more of the broad gender diversity found within the transgender community, it still seems likely that there will always be a need for a diagnostic category for people who are clinically symptomatic and in need of treatment. We, therefore, anticipate that no matter how inclusive the diagnosis becomes, there will continue to be a need for the GID NOS diagnosis.

Should the Diagnosis Have a Different Name?

The work group separated this question into two subquestions: Should we retain the term GID, and should we retain the term GID NOS? We are in favor of keeping the NOS designation. This recommendation is based upon two primary conditions. First, as long as there is a diagnosis of GID, the diagnosis GID NOS will be of use to those who do not fulfil all criteria in the diagnosis GID for children, adolescents, or adults. Second, the name of GID NOS will follow changes to the name of GID. For example, if Gender Identity Disorder becomes Gender Identity Variance, then the NOS diagnosis would become GIV NOS.

The work group reached consensus on the need for changing the name of the GID diagnosis. Some group members would like to see removal of the term *disorder* because it has a negative connotation and may enhance the potential for discrimination and pathologization of a natural variant of human experience. However, persons with threshold levels of dysfunction (i.e., meeting the clinical significance criterion) do have impairment, just as persons with depression

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(another common human experience) meet criteria for major depressive "disorder" when they reach a certain threshold of impairment. Although we did not reach consensus on a preferred alternative name for the diagnosis, our top choices were: Gender Dissonance NOS, Gender Discordance NOS, Gender Dysphoria Spectrum NOS, and Gender Identity Variation Causing Severe Distress NOS.

Where Should GID NOS Diagnosis Appear in the DSM 5*?*

The diagnosis should appear after the GID diagnosis, as it does now. We highly recommend removal of both of these diagnoses from the chapter on sexual disorders. GID and GID NOS are diagnoses pertaining to identity, not sexuality, and would more appropriately be listed in a separate group.

Which Diagnostic Criteria Do We Propose for GID NOS?

The current diagnostic criteria for GID NOS in the *DSM-IV-TR* are as follows:

> **302.6 Gender Identity Disorder Not Otherwise Specified.**
> This category is included for coding disorders in gender identity that are not classifiable as a specific Gender Identity Disorder. Examples include:
>
> 1. Intersex conditions (e.g., androgen insensitivity syndrome or congenital adrenal hyperplasia) and accompanying gender dysphoria.
> 2. Transient, stress-related cross-dressing behaviour.
> 3. Persistent preoccupation with castration or penectomy without a desire to acquire the sex characteristics of the other sex. (p. 582)

Below are our proposed alterations to the current diagnostic criteria:

> This category is included for coding disorders in gender identity with significant clinical distress, that are not classifiable as a specific Gender Identity Disorder (or the new name). Examples include:
>
> 1. Transient, stress-related cross-dressing behavior with clinically significant levels of gender dysphoria.
> 2. Persistent preoccupation with castration or penectomy without a desire to acquire the sex characteristics of the other sex and with clinically significant levels of gender dysphoria.
> 3. Desire for partial gender adjustment by hormonal or surgical interventions in order to relieve feelings of gender dysphoria but not specifically intended to move the individual toward a traditional gender presentation or traditional gender role.
> 4. Clinically significant levels of gender dysphoria associated with oscillation between male and female gender identity or other nontraditional forms of gender identity such as those that combine male and female or that reject both male and female.

DISCUSSION

The above recommendations add a clinical significance criterion for GID NOS, as is the convention for other diagnoses. This should prevent the "labelling" of nonproblematic gender variant behaviors/feelings as a clinical diagnosis. Furthermore, the current *DSM-IV-TR* diagnosis excludes individuals who have an intersex condition or disorder of sex development, as if they may not also have legitimate gender identity concerns. We propose that in *DSM 5*, this exclusionary criterion be removed for the diagnosis for children, adolescents, or adults, so that individuals with an intersex condition or a disorder of sex development AND gender dysphoria, can receive the GID diagnosis instead of the NOS diagnosis if they meet the basic criteria. Therefore, individuals with an intersex condition or disorder of sex development would not necessarily be included as an example in the description of the NOS diagnosis. A specifier code (e.g., "with Disorder of Sex Development")

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would retain the ability to conduct research on those with and without disorder of sex development.

We recommend retaining some variant of two of the three existing clinical examples in the *DSM-IV*, and adding two more. Examples 1 and 2 (above) include the addition of the requirement that the individual have some gender dysphoria and the supposition that this gender dysphoria is connected to the presenting symptom. We would also like to see additional clinical examples that illustrate the application of the diagnosis to individuals with other gender variant identities who experience clinically significant symptoms of gender dysphoria. Examples 3 and 4 are more inclusive of clinical presentations that involve nontraditional forms of gender identity. As argued above, we have omitted the Diagnosis of Sexual Disorder conditions from the examples, since we think that they should be included in the standard GID diagnosis.

ADDITIONAL COMMENTS

At this time it is not known how the *DSM 5* will address gender identity concerns. Our group work proceeded under the assumption that there would be a diagnosis analogous to GID, necessitating an accompanying NOS diagnosis. Although we do recognize that if the *DSM 5* GID-equivalent diagnosis were broadened, individuals who would currently fall under GID NOS might be included in the GID diagnosis for children, adolescents, or adults. But even then, we believe that there will continue to be a need for a diagnosis for individuals with gender concerns who do not fit the primary diagnoses. This is necessary to facilitate access to treatment and privileges that likely will require the existence of a legitimate, well-defined diagnosis. Another aspect, considered essential by our working group for a diagnosis pertaining to gender identity concerns, is that the diagnosis must reflect the variations in the life course found among this population. An individual's experience of gender identity may change over the lifetime. For example, it would be expected that an individual once diagnosed with the NOS diagnosis, at another time in their lives might meet criteria for the main diagnosis or, alternatively, might have resolved their gender dysphoria.

Recent decades have seen a marked growth in the number of transgender people who request medical and mental health services and a concomitant increase in scholarship and treatment options for these populations. Medical and mental health interventions that evolved to serve a traditionally transsexual population are now being employed by people with a range of gender identities and experiences. The World Professional Association for Transgender Health publishes the *Standards of Care for Gender Identity Disorders* (Meyer et al., 2001). These standards state that the goal of treatment is "comfort with the gendered self." We believe that the NOS diagnosis broadens the possibility of treatment for people of all genders to achieve such comfort. The NOS diagnosis provides clinical freedom and flexibility for the practitioner so that treatment can be tailored to the individual's specific needs. The diagnosis also allows for the great variety in human experience and for unexpected and unique clinical situations.

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